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ABSTRACT

Guidelines are presented for working with parents of learning disabled children in a collaborative clinician-parent program. Parents are explained to need guidance and support in managing the child at home, in dealing with family members and others who don't understand the problem, and in understanding the professional's language. To be effective with parents, the clinician is advised to follow six rules, including using simple language, specifying clear and honest goals for the child, and avoiding contributing to the parents' guilt. Components of the collaborative parent-clinician program are described, such as weekly parent group meetings and parent association sessions. (CL)

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CLINICIAN AND PARENT: PARTNERS FOR CHANGE**

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A major problem presented by the learning-disabled child is the abrasive interaction between him and his environment. He provides a constant source of friction to those around him, who in turn often react in ways that create further friction. To help this child, it may be necessary to modify his environment, and at the same time minimize his handicapping and abrasive behaviors. Modification of the home environment can be achieved only by employing the cooperation of the child's parents. Only by involving parents as collaborators (rather than objects, or patients, or cases, or guilt-bearing child-abusers) can one maximize the possibility of providing relief and assistance for the child. All of this must be accompanied by a program that helps him acquire the pre-academic and academic skills that he needs.

The Learning Disabilities Clinic at Coney Island Hospital, part of a mental health unit in a public hospital setting, has enlisted the cooperation and assistance of parents of the learning-disabled as therapists for other learning-disabled children, and

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as co-therapists in dealing with their own children. This is accomplished by means of a program involving the sharing of skills via workshops and training programs, foregoing technical terminology, and stressing the development of trust via open and reciprocal communication. In this program, parents and the clinic become collaborators in a joint effort.

The Parents

The parents whose children attend this clinic are in the main members of the working class, and some of them are unemployed. The parents are under constant strain. In most cases, the families are multiply handicapped, suffering from economic stress and many medical problems, in addition to having one or more children who fail to learn properly, and about whom the schools complain constantly. Famililial histories of learning difficulties are frequently encountered. Many of the children have only one parent. Few parents have attended college; some have completed high school, and many have never gone that far. They are often inarticulate, and poorly equipped to deal with the schools. They are generally mistrustful of mental health services, and are willing to have their children attend a "learning" clinic in the hope that success in learning will provide social and economic mobility for the child. In some cases, however, they come to the clinic only because they are forced to do so by the schools.

The parent, when he first comes to the clinic, may be shopping for services, moving from one agency or clinic to another in search of a solution to his problem. The home, which in any case may be troubled, or even turbulent, is further strained by the child's behavior

and failure to learn. The parent is bewildered, confused, resentful, frustrated and often punitive. A feeling of helplessness and of general ineffectiveness is pervasive.

What do the parents need? The parents need answers to a multitude of troubling questions; they need guidance, and they need reassurance.

They want to know why there are so many problems surrounding their child. If a label, or a diagnosis, has been attached to the child, what does it really mean? What is the prognosis? What may be expected in the future? If medication has been prescribed for the child (or even suggested), they want to know more about it. What are its potential side effects, and its potential long-term effects? What alternatives are available?

The parents need guidance in managing the child at home, and in educational planning. They need advice regarding educational expectations for this child, and guidance in obtaining services, including optimum class placement. They want to know how to deal with daily crises, and with that insidious, daily nightmare, homework.

Parents need support and guidance in dealing with grandparents, neighbors, pediatricians, fathers, teachers. These people can be friends and allies, except that they usually don't understand the problem, sit in judgment, and have inappropriate expectations. They may call the child lazy, uncooperative, and uncaring; they fail to recognize that the child is doing his best and has very real handicaps. The mother is usually blamed for not "bringing up" the child properly.

Parents need help in understanding the language of the professional. They need help in walking the thin line that leads to getting the most and best services for the child (of the few that are available) without offending the professionals and the establishment.

Parents seek relief from harrassment and distress, and from guilt; they seek a reversal of the cycle of failure, disappointment and misery with this child. And they seek acceptance, respect, support, confidence, encouragement, compassion, humor, kindness, courtesy, and lots more.

All of these we, the clinicians, try to give them--plus one more: a cup of coffee.

The Clinicians

The Learning Disabilities Clinic is staffed by a small group of special educators, too few to stem the flood of problems presented by children from the local public and parochial schools. In order to deal with these problems, clinic and clinicians constantly seek the cooperation of others. A constant effort is made to enlist the cooperation of school personnel, of other agencies, of volunteers, and, most important, the parents of the children.

What, then, is the role of the clinician in working with the parents? The clinician can interpret to the parents the label or diagnosis attributed to the child. He can discuss the uses and misuses of labels. He can relieve the parents of destructive guilt. He can help set realistic expectations. He can coordinate the development of a viable treatment plan, including medical, psychological, educational, and home management components. He can help locate

appropriate services, and serve as advocate in securing those services. He can provide guidance in dealing with social pressures generated by teachers, neighbors, relatives. To be effective in this role, the clinician observes several simple rules.

Do's and Dont's of a Collaborative Clinician-Parent Program

1. Use simple language in communicating with teachers and with parents. Language problems prevail among children with learning problems, and similar problems of communication exist among professionals, between professional disciplines, and between professionals and parents. Jargon and technical language are used by many to cloak confusion and lack of clarity. Simple, clear language expedites communication, and builds trust. Rather than say, "I find it difficult to verbalize in terms that you will find comprehensible," the clinician should say, "It's hard to explain."

2. The clinician and the parent must be clear about the goals for this child, and for children generally. They must be honest, and explicit. Are clinician and parents concerned with the child's learning to read? Or to have good table manners? Or are they even now concerned about his being accepted into medical school? Each of these requires a different plan; and some of them may be unrealistic for this child, or inappropriate for the moment.

3. Teacher and clinician are more helpful when they explain to parents clearly what they are doing, and why they are doing this. For example, parents may think the use of games or motor activity during a tutorial session is a waste of time for their children, unless they are told how the games help teach Jane to sound out her short vowels, that

the ball game teaches Peter the concepts of left and right which are important for his academic learning. Similarly, the value of an activity group or a therapy group may not be appreciated unless clinicians explain that the art activity group helps Peter and Jane improve their relationships with children and adults. In this group Peter learns to wait his turn, while Jane learns to participate in activities which she has in the past tended to avoid. As they understand the "why" for each activity, parents become more cooperative (rather than resistant).

4. There must be acceptance of, and respect for individual limitations-in parents, in teachers, and in clinicians.

> John was reported to have been physically abused by his father. For several years, John's father had refused to show his face at the clinic. Several months ago he started to bring John in for his appointments, and to sit in the waiting room while John was tutored. Though he had been reported to be an ogre, staff chatted with him casually and pleasantly during his visits. Treated with respect and acceptance, he relaxed. When a fathers group was formed, he attended. And he spoke up. When the question of corporal punishment was raised, he announced, "I learned it. It doesn't pay." Apparently he now felt comfortable and trusting enough to share his experience.

Clinicians are forgetful and ineffectual at times. Parents can learn to accept the human limitations of the clinic and clinician, as they themselves are accepted.

5. Beware of the "mother abuse" bandwagon; avoid heaping guilt on the parents.

Parents of children with problems are often victims of home situations in which they are frustrated and helpless; much of this has developed from circumstances that were well beyond their control.

They seek counsel on how to help the child, and how to change the relationship between the child and the parents or the siblings or friends or neighbors. Instead, they are burdened with abuse, with blame, and with guilt for having done an awful job. The mother, in particular, is subjected to such abuse and to great feelings of guilt.

This approach is destructive. It interferes with wholesome family relationships and hampers planning for good home and school management.

For example, consider the following example of Amy.

> At the age of 4-1/2, Amy's speech was limited to a few words that were difficult to understand. She was always on the go, constantly moving, climbing, running, never pausing to concentrate on anything -- "wild" they called her; but she was not retarded. Her mother was thin, worn, and drained. Near exhaustion, she pleaded for help.
>
> Amy was accepted and would attend a special class that would provide hope and help for Amy and her mother. Mrs. Kaye had to bring Amy daily--travelling one hour each way in the trolley car. The trip was a small price to pay for the schooling.
>
> Every day, on the trolley car, Amy was her usual self--climbing, running, screaming (unintelligibly), and Mrs. Kaye, as usual, restrained her as well as she could, grateful that the trolley car provided natural boundaries so that she did not have far to chase the child.
>
> And everyday, some passenger would scold Mrs. Kaye for her failure to bring up her child properly. Several times a week, some neighbor would lecture to Mrs. Kaye on how poorly she had raised her child. They never considered the possibility that Amy's behaviors were based on constitutional problems, diagnosed as "brain injured" by the clinical team at the treatment center.
>
> They were collaborators in one of our most handy and destructive social weapons;-used by the teacher, by clinicians, fathers, mothers-in-law, and adolescents-mother abuse.

6. Share with the parents simple principles of child development, and of good management and educational practice.

a. Accentuate the positive. Every child has positives, and these must be recognized and encouraged. At the same time, the negatives must also be acknowledged and attended to. George is a remarkable skater, while his penmanship is illegible. He teaches other children to skate; at the same time, he receives special assistance with penmanship instruction. For this, special paper and a multi-sensory approach are planned. In addition, he is encouraged to use the typewriter. His self-esteem is supported by the respect given to him as a fine skater.

b. Parents are discouraged from tutoring their own children. Because patience and objectivity are prime requisites for effective tutoring, parents should be urged not to tutor their own children. They are assured that they will be far more patient with the child of another family, and are therefore encouraged to tutor someone else's child. They will achieve, in addition, greater appreciation of their own child, as they become familiar with the problems and foibles of another child who has learning problems.

c. Parents are cautioned not to nag.

Tell the child what is required, and let him suffer the consequences if he fails to do it. Nagging breeds nagging. If the child knows you will remind him again and again, he will hold you responsible for not reminding him the thousand and oneth time.

d. Do not compare the child with his siblings. Compare the child with himself: today he has moved far ahead of where he was two months ago. Every child in the family is different; it is unfair to compare them to each other. The concept of individual differences must be kept in mind.

e. Set realistic goals, with small steps, so that the child may be assured of success. Only if he is successful will he be motivated to continue to learn.

f. Keep in mind that many of these children have problems in language, memory and sequencing, and also difficulties in abstraction. Give one instruction at a time; avoid or explain idioms; teach concepts.

g. Parents should know how the schools <u>should be</u> so that they may be effective in making change, particularly for their own child with learning problems. Parents should understand the importance of gearing individual tasks and materials to a child's functional level rather than to his age or grade level.

<u>The Parent Program in Action at the Clinic</u>

The waiting room, where parents wait while their children are tutored or evaluated, is a "Relaxercizer." Here a cup of coffee is always available. Parents chat with each other, share problems, and offer each other support. Staff members are available for "Button-hole" conferences. Younger siblings are observed informally, and on occasion it is noted that perhaps it would be appropriate to evaluate one of them as a likely candidate for service at the clinic. A recipe book is on the table; parents and staff exchange recipes.

Here is the market-place for mutual support, therapy, education, case finding, and the building of trust.

In addition, the following activities have been developed:

a. Parent groups meet with a staff member weekly on mornings when many parents bring their children in. Mainly, the participants are mothers; occasionally a few fathers attend. These are seen by the parents as problem-solving groups, and the clinicians as facilitators, rather than as therapy groups. In one group sat a psychiatrist and an illiterate mother, both parents of learning disabled children. Also present was a mother of four learning disabled boys. One very anxious mother in the group saw her boy as a failure and applied too much pressure to him. Responding to group discussion, she was able to relax; as she relaxed, her son began to make progress, and he is now in a class for the gifted.

b. A For Men Only group for fathers, led by a male staff member, met one evening a week last year. The response was enormous, and the series of meetings proved to be invaluable. Fathers had many questions, resentments and biases that could be discussed only in this kind of non-threatening atmosphere. This proved to be our most effective technique for reaching the fathers who were usually the most difficult to reach. Unfortunately, the series had to be discontinued because of the unavailability of a staff member to meet with the group.

c. When the clinic was threatened with destruction because of New York City's fiscal crises, parents formed an association to save the clinic. They maneuvered to elect one of their members to membership on the Community Board of the Hospital. And they organized plant sales, toy sales, and raffles to raise money for a scholarship fund to pay the clinic fees of those under greatest financial stress.

This type of mobilization is impressive in a group of parents who are not accustomed to group action, and who generally see themselves as helpless and ineffectual, and therefore usually deport themselves in that way.

d. The clinic runs courses to train parents in the community to volunteer to tutor in the schools. Many of the clinic parents take these courses. As a result of their increased understanding of child development and of educational concepts and problems, they are able to deal with their own children in an accepting and realistic way.

In addition, some of the parents are then invited to tutor at the clinic while their own children are being tutored. They have proven to be fine tutors; one of them remained as a tutor even after her daughter had been "graduated."

e. Parent Sharing

Whenever possible, we share with the parents our reports, our joys, our problems and our work. When they read

the psycho-educational evaluation describing their children, we gain their confidence and trust. When they see the films we have produced (one depicting a tutorial session, and two explaining psycho-educational assessment) they are once more impressed with the commonality of the scenes they view and the problems that they experience.

f. Parent-School Relations

We give parents confidence in dealing with the school, and with such typical issues as holdover, promotion, and homework. Frequently something is wrong with the child's school management, but the parents feel ineffectual in dealing with these problems. If warranted, we confirm their intuitions, and support them. Sometimes we disagree with their hunches. For example, a parent may insist that promotion will be better for her child than holdover for another year in the same grade. If we feel that in this case a holdover will be more helpful, but we cannot convince her, we nevertheless continue to work with her and the child.

In short, we work with the parents at their level, without patronizing them. We try to help them accept and cope with the problems presented by a learning-disabled child. We support their search for the best services available, and work with them for the development of more and better services.

If there is any secret to the success of our program, it is contained in our working philosophy, which is to maintain a non-dogmatic, non-authoritarian approach to parents.
We do not sit in judgment.